

## ARTICLES

# PRIVACY IN GENETIC TESTING: WHY WOMEN ARE DIFFERENT

SUSAN B. APEL\*

### I. INTRODUCTION

Two years ago, I attended an international conference on genetic testing in Rennes, France, where one panel was scheduled to discuss privacy and genetic testing. The specific topic was whether family members ought to have access to an individual's test results. My assumption, an admittedly naïve and ill-informed one, was that no one, including family members, had any right to this information. Even more naïve and ill-formed was my second assumption: that the first assumption was shared and universal. I was shocked, therefore, when one of the presenters articulated a position in favor of physicians' sharing an individual's test results with family members. His views were quickly echoed by a member of the audience who identified himself as a physician from Canada. When the time came for questions from the participants, I asked whether anyone other than me had concerns about the privacy rights of individuals, and whether there was any recognition by the speakers of their own, perhaps questionable, assumptions about families being benign and loving entities. The response I received was a question: Was I an American? When I responded that I was, the explanation for my position seemed evident to everyone. Americans have an intense interest and concern for privacy, presumably in ways that non-Americans do not. I could not argue with this observation about American culture and jurisprudence, still I left the conference with a great deal of unease. Even within my own United States, I realized that I knew little about a physician's duty of confidentiality and that the law on the issue was scarce. I also found myself questioning what I perceived to be the gendered nature of the debate, particularly the notion that individuals would have little to fear from families' knowledge of their genetic status. In my gut, I wondered if that were true for women.

This Article is my attempt to deal with the best gift that a conference can bestow: an awakened curiosity and enough of a sense of foreboding to try to answer the question. Part II is a primer on medical perspectives regarding privacy, including the positions taken on the issue by the

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\* Professor, Vermont Law School and Adjunct Professor, Dartmouth Medical School; J.D., 1977, Northeastern University School of Law. I am grateful to Abigail Sykas for her work on this manuscript.

American Medical Association and various other professional organizations. It includes the results of several studies of physicians' responses to hypotheticals concerning patient confidentiality as well as a discussion of patients' expectations. Part III presents the existing legal perspective. Part IV looks at the question of why women may have particular concerns regarding privacy and genetic testing, including the potential for domestic violence, disruption of intimate relationships, and the loss of employment within the family.

## II. THE MEDICAL PERSPECTIVE

How people feel about the privacy of medical information, including results of genetic testing, seems complicated and at times contradictory. On one hand, people evidence some trust in their personal physicians.<sup>1</sup> While most people cannot quote verbatim the Hippocratic oath—“[w]hatever, in connection with my professional practice, or not in connection with it, I see or hear, in the life of men, which ought not to be spoken of abroad, I will not divulge, as reckoning that all such should be kept secret”<sup>2</sup>—the term “Hippocratic oath” is known and understood by most patients. Patients believe that doctors swear to keep their patients' secrets, and the oath therefore represents a sense of trust and confidentiality that many patients view as the hallmark of their relationships with their doctors. The law, and in particular the law as portrayed in popular culture, adds to this sense by recognizing a physician-patient privilege that generally prevents a doctor from testifying about a patient's medical information without the patient's consent. When it comes to the issue of genetic testing, patients who trust their doctors to maintain confidentiality in medical care would most likely include genetic test results to be within the parameters of what must be kept secret.

On the other hand, there is also a sense of unease. In one poll by the Health Privacy Project of the Institute for Health Care Research and Policy at Georgetown University, one in five individuals believed that a *health care provider*, insurance plan, government agency, or employer had improperly disclosed personal medical information, with one half of these people believing that such disclosure resulted in personal embarrassment or harm.<sup>3</sup> The same poll showed that one in six people had done something out of the ordinary to keep personal medical information confidential.<sup>4</sup> This behavior included withholding information from their health care providers.

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<sup>1</sup> *AMA Survey: Americans Trust Physicians on Genetic Testing Information*, Advocacy & Communications, at <http://www.ama-assn.org/ad-com/releases/1998/980421.htm> (March 11, 1998) (on file with author). See also *National Survey: Confidentiality of Medical Records*, California Health Care Foundation, at <http://www.chcf.org> (last visited Jan. 31, 2000) [hereinafter *California Healthcare Foundation National Survey on Confidentiality*] (showing that 60% of adults nationally and 62% of California residents trust their doctors to keep information confidential all or most of the time) (on file with author).

<sup>2</sup> Roberta M. Berry, *Genetic Revolution and Physician Confidentiality: The Role of the Old Hippocratic Virtues in the Regulation of the New Genetic Intimacy*, 18 J. LEGAL MED. 401, 408–09 (1997) cited in B. FURROW ET AL., *BIOETHICS: HEALTH CARE LAW AND ETHICS* 30 (1990).

<sup>3</sup> *California Health Care Foundation National Survey on Confidentiality*, *supra* note 1.

<sup>4</sup> *Id.* (italics added).

Another survey showed that 25% of respondents reported that they or a member of their family had personally paid for a medical test or treatment rather than risk a breach of confidentiality by submitting a claim to an insurance program.<sup>5</sup>

This seemingly fractured view of privacy in the doctor-patient relationship leads to questions about the meaning of the Hippocratic oath, and whether doctors can, should, or must break the confidences of their patients. While these questions have resonance for all medical information, they have arisen specifically in the discourse surrounding genetic testing. One view is that genetic information is so unique and comprehensive that it heightens the need for privacy.<sup>6</sup> “Counselors report that persons in families affected by genetic conditions perceive genetic information as more personal, revealing, and stigmatizing than other medical information.”<sup>7</sup> Another view is that genetic information should not be viewed as different from other medical information,<sup>8</sup> but rather that its arrival on the medical scene has simply renewed the existing concern for confidentiality. Finally, a third view shifts the focus entirely by insisting on privacy, but raising the question of to whom privacy is owed—the individual being tested or the family whose genetic secrets are captured in the test results?<sup>9</sup>

This Part will examine prevailing professional standards regarding confidentiality of genetic test results, beginning on one end of the spectrum with the view that most standards enshrine confidentiality, and moving across the continuum. This Part will then examine what health care providers and patients have stated about their own views and expectations when these standards are applied in a clinical setting.

We begin with what we might term the most absolute view of confidentiality and privacy—a strict interpretation of the text of the Hippocratic oath—that doctors can be counted on to keep their mouths shut. The absolutists in the area of genetic testing are not doctors at all, but genetic counselors. Genetic counselors are not physicians but are individuals specifically trained (usually with a masters-level degree from only a handful of programs) to assist patients in making choices about

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<sup>5</sup> 1993 Lou Harris Poll, Electronic Privacy Information Center, at <http://www.epic.org/privacy/medical/polls.html> (last visited Apr. 14, 2001) (citing Harris Equifax, *Health Information Privacy Survey* (1993) (on file with author)).

<sup>6</sup> George J. Annas, *Drafting the Genetic Privacy Act: Science, Policy, and Practical Considerations*, 23 J. LAW, MED. & ETHICS 360; George J. Annas, *Genetic Privacy: There Ought to Be a Law*, 4 TEX. REV. L. & POL. 9 (1998); Francis S. Collins, *Medical and Ethical Consequences of the Human Genome Project*, J. CLINICAL ETHICS 260, 264 (1991).

<sup>7</sup> Barbara Bowles Biesecker, *Privacy in Genetic Counseling*, in GENETIC SECRETS: PROTECTING PRIVACY AND CONFIDENTIALITY IN THE GENETIC ERA 108, 109 (Mark Rothstein ed., 1997) [hereinafter GENETIC SECRETS] (citing Clair Leonard, Gary Chase, & Barton Childs, *Genetic Counseling: A Consumer's View*, NEW ENG. J. MED. 287, 433–39 (1972)).

<sup>8</sup> Thomas H. Murray, *Genetic Exceptionalism and “Future Diaries”*: *Is Genetic Information Different from Other Medical Information?*, in GENETIC SECRETS, *supra* note 7, at 60; Mark A. Rothstein, *Why Treating Genetic Information Separately Is a Bad Idea*, 4 TEX. REV. L. & POL. 33 (1999).

<sup>9</sup> Lori B. Andrews, *Gen-Etiquette: Genetic Information, Family Relationships, and Adoption*, in GENETIC SECRETS, *supra* note 7, at 255, 256. See also DOROTHY C. WERTZ, JOHN C. FLETCHER, & KARE BERG, WORLD HEALTH ORG., GUIDELINES ON ETHICAL ISSUES IN MEDICAL GENETICS AND THE PROVISION OF GENETIC SERVICES (1995).

genetic testing and its results. The National Society of Genetic Counselors Code of Ethics contains a strong declaration in favor of confidentiality:

The counselor-client relationship is based on values of care and respect for the client's autonomy, individuality, welfare, and freedom. The primary concern of genetic counselors is the interests of their clients. Therefore, genetic counselors strive to . . . [m]aintain as confidential any information received from clients, unless released by the client.<sup>10</sup>

The precise wording does not appear to include results of genetic tests, because such results would not be information received from clients. An explication of the Code broadens the concept, however, by stating the following:

The value of confidentiality . . . is virtually universal. . . . The committee considered the possibility that the sharing of an identified client's information may be justified on the basis of the counselor's judgment in a special situation, but rejected the idea because the various scenarios within which this could be possible are endless, making confidentiality meaningless.<sup>11</sup>

Thus, "information received from clients" appears to include "client information" without regard to source, perhaps in much the same way that lawyers are required to hold confidential both communications directly from clients and any other information they may learn in the course of representation.<sup>12</sup> One genetic counselor writes clearly on the subject of disclosure of genetic testing that "[t]his model of clinical practice of medicine continues to dictate nondisclosure to other family members . . . even if disclosure . . . is clearly in the best interests of relatives."<sup>13</sup>

Perhaps less well known and understood by patients is what appears to be the prevailing view of patient privacy, which starts with confidentiality as a general rule, but builds in exceptions. The American Medical Association's Code of Professional Ethics states that "a physician shall . . . safeguard patient confidences within the constraints of the law."<sup>14</sup> In a section on confidentiality, the AMA goes on to state that:

The information disclosed to a physician during the course of the relationship between physician and patient is confidential *to the greatest possible degree*. . . . The physician should not reveal confidential communications or information without the express consent of the patient, unless required to do so by law.

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<sup>10</sup> Nat'l Soc'y of Genetic Counselors, *National Society of Genetic Counselors Code of Ethics*, 1 J. GENETIC COUNSELING 41, 42 (1992).

<sup>11</sup> Judith L. Benkendorf, Nancy P. Callanan, Rose Grobstein, Susan Schmerler, & Kevin T. Fitzgerald, *Explication of the National Society of Genetic Counselors (NSCG) Code of Ethics*, 1 J. GENETIC COUNSELING 31, 36 (1992).

<sup>12</sup> MODEL RULES OF PROF'L CONDUCT R.1.6 (2000); MODEL CODE OF PROF'L RESPONSIBILITY DR 4-101 (2000).

<sup>13</sup> Eugene Pergament, *A Clinical Geneticist Perspective of the Patient-Physician Relationship*, in GENETIC SECRETS, *supra* note 7, at 103.

<sup>14</sup> AM. MED. ASS'N, CODE OF MEDICAL ETHICS: CURRENT OPINIONS WITH ANNOTATIONS xiv (1994) (citing the preamble); BUREAU OF NAT'L AFF., MEDICAL ETHICS: CODES, OPINIONS, AND STATEMENTS 7 (Baruch A. Brody et al., eds., 2000) [hereinafter MEDICAL ETHICS].

The obligation to safeguard patient confidences is subject to certain exceptions which are ethically and legally justified because of overriding social considerations. Where a patient threatens to inflict serious bodily harm to another person . . . the physician should take reasonable precautions for the protection of the intended victim. . . . Also, communicable diseases, gun shot and knife wounds should be reported as required by applicable statutes or ordinances.<sup>15</sup>

On the specific issue of genetic testing, the structure closely follows that of the AMA's view that confidentiality is the general rule, but there are exceptions. Among several professional groups, there is substantial agreement about which exceptions are proper. For example, the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Medicine proposed that it is proper for a health care professional to reveal the results of genetic testing to family members over a patient's objection when:

1. reasonable efforts to elicit voluntary consent to disclosure have failed;
2. there is a high probability both that harm will occur if the information is withheld, and the disclosed information will actually be used to avert harm;
3. the harm that identifiable individuals would suffer would be serious; and
4. appropriate precautions are taken to ensure that only the genetic information needed for diagnosis and/or treatment of the disease in question is disclosed.<sup>16</sup>

Other professional organizations, such as the Institute for Medicine and the American Society of Human Genetics ("ASHG"), have adopted similar positions. The former has stated that the "strongest case" for warning by a health care professional would exist if the above conditions were satisfied;<sup>17</sup> ASHG agrees, but adds at least two wrinkles. The first is that the harm to the identified relatives must be "highly likely to occur and . . . serious, imminent, and foreseeable," requiring only that the disease be "preventable, treatable, or that medically accepted standards indicate that early monitoring will reduce the genetic risk."<sup>18</sup> The second, a balancing test,

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<sup>15</sup> MEDICAL ETHICS, *supra* note 14, at 29 (citing Rule 5.05, issued Dec. 1983, updated June 1994) (emphasis added); Laurence R. Tancredi, *Collection and Disclosure of Genetic Information*, in THE GENETIC FRONTIER: ETHICS, LAW, AND POLICY 47, 50 (Mark S. Frankel & Albert Teich eds., 1994).

<sup>16</sup> PRESIDENT'S COMM'N FOR THE STUDY OF ETHICAL PROBLEMS IN MED. AND BIOMEDICAL AND BEHAVIORAL RESEARCH, SCREENING AND COUNSELING FOR GENETIC CONDITIONS: A REPORT ON THE ETHICAL, SOCIAL, AND LEGAL IMPLICATIONS OF GENETIC SCREENING, COUNSELING AND EDUCATION PROGRAMS 44 (1983) [hereinafter PRESIDENT'S COMM'N].

<sup>17</sup> The language favored by the Institute for Medicine is as follows:

The committee recommends that confidentiality be breached and relatives informed about genetic risks only when attempts to elicit voluntary disclosure fail, there is a high probability of irreversible or fatal harm to the relative, the disclosure of the information will prevent harm, the disclosure is limited to the information necessary for diagnosis or treatment of the relative, and there is no other reasonable way to avert the harm.

INST. OF MED., ASSESSING GENETIC RISKS: IMPLICATIONS FOR HEALTH AND SOCIAL POLICY 278 (Lori B. Andrews et al. eds., 1994).

<sup>18</sup> MEDICAL ETHICS, *supra* note 14, at 248.

requires that “[t]he harm that may result from failing to disclose . . . outweigh the harm that may result from disclosure.”<sup>19</sup>

To better understand this exception, it may be useful to focus on the particular disease, which—with the exception of the balancing test added by the ASHG—is determinative of most of the critical factors of the test. One relatively easy example is Huntington’s disease.<sup>20</sup> Because neither treatment nor a means of prevention is available for Huntington’s, confidentiality would likely be maintained. Another example with the opposite result is hemochromatosis, a genetic disease which causes an individual to retain too much iron in the blood, is treated by regular blood donations (phlebotomies), and thus, is at the opposite end of the spectrum from Huntington’s disease in terms of the availability of treatment.<sup>21</sup>

Genetic propensity for breast cancer, the carrying of the BRCA-1 or BRCA-2 gene, might be more problematic in application. Carriers of the gene have a significantly greater than average chance of developing cancer as measured against the general population.<sup>22</sup> The question is whether, under the guidelines, this translates into a “high probability.”<sup>23</sup> Treatment involving drugs such as tamoxifen shows promise,<sup>24</sup> even if not definitive, whereas prophylactic mastectomy and/or oophorectomy<sup>25</sup> would certainly qualify as a “treatment” or possibly even a “prevention.” When viewed against the more expansive language of the ASHG—that at a minimum, early monitoring would reduce the genetic risk<sup>26</sup>—it appears as if disclosure would be permitted under the guidelines. Thus, in what many patients may

<sup>19</sup> *Id.* at 249. See also AM. SOC’Y OF FAMILIAL GENETIC INFORMATION, *Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUM. GENETICS 474 (1998).

<sup>20</sup> Huntington’s disease is an untreatable, hereditary autosomal disorder that is characterized by involuntary movements and progressive dementia. HARRISON’S PRINCIPLES OF INTERNAL MEDICINE 2014 (E. Braunwald et al. eds., 11th ed. 1987). For a compelling narrative of a family’s experience with Huntington’s Disease, see ALICE WEXLER, *MAPPING FATE: A MEMOIR OF FAMILY, RISK, AND GENETIC RESEARCH* (1995).

<sup>21</sup> My thanks to Walter Noll, M.D., Dartmouth-Hitchcock Medical Center, Lebanon, NH for his example of hemochromatosis. See also Allen Buchanan, *Ethical Responsibilities of Patients and Clinical Geneticists*, 1 J. HEALTH CARE L. & POL’Y 391, 392–93 (1998).

<sup>22</sup> Females found to carry a mutation in BRCA1 have an 80–90% lifetime risk of breast cancer, a 40–65% lifetime risk of ovarian cancer, and an increased risk of colon cancer. Caryn Lerman, Steven Narod, Kevin Schulman, Chanita Hughes, Andres Gomez-Caminero, George Bonney, Karen Gold, Bruce Trock, David Main, Jane Lynch, Cecil Fulmore, Carrie Snyder, Stephen J. Lemon, Theresa Conway, Patricia Tonin, Gilbert Lenoir, & Henry Lynch, *BRCA1 Testing in Families with Hereditary Breast-Ovarian Cancer: A Prospective Study of Patient Decision Making and Outcomes*, 275 J. AM. MED. ASS’N 1885 (1996).

<sup>23</sup> PRESIDENT’S COMM’N, *supra* note 16.

<sup>24</sup> Steven A. Norad, Jean-Sébastien Brunet, Paviz Ghadirian, Mark Robson, Ketil Heimdal, Susan L. Neuhausen, Dominique Stoppa-Lyonnet, Caryn Lerman, Barbara Pasini, Patricia de los Rios, Barbara Weber, & Henry Lynch, *Tamoxifen and Risk of Contralateral Breast Cancer in BRCA1 and BRCA2 Mutation Carriers: A Case-Control Study*, 356 LANCET 1876 (2000).

<sup>25</sup> Karla Harby, *BRCA Mutation Carriers with Breast Cancer Often Opt for Prophylactic Oophorectomies*, Huntsman Cancer Institute, at <http://www.huntsmanccancer.org/content/reuters/2000/09/26/20000926clin001.html> (Sept. 26, 2000) (citing a study by Kenneth Offit, M.D., Memorial Sloan-Kettering Cancer Center).

<sup>26</sup> Note, however, that even scientists are not in agreement on this issue. “Thus far, there have been no randomized clinical trials indicating that either greater monitoring of women with the mutation or prophylactic mastectomy improves the quality of life, psychological well-being, or medical outcome of the women who have a mutation in the breast cancer gene.” Andrews, *supra* note 9, at 265. See also Lerman et al., *supra* note 22, at 1886 (referring to “the absence of proven strategies for preventing cancer in carriers, (including surgical prophylaxis”).

regard as a highly sensitive genetic test—a test for breast cancer—doctors would be able to disclose the test results to the patient’s relatives, even over the patient’s own objections.<sup>27</sup>

Another view of confidentiality in genetic testing is what has been referred to as the “genetic Miranda warning.”<sup>28</sup> This is the view that patients should be warned in advance that confidentiality is not guaranteed, and that under some circumstances, such as those outlined above, a doctor is free to contact a patient’s family members with the test results over the patient’s objection. Patients can then decide prior to the test whether or not they wish to proceed with the testing. While such a warning may compromise patient autonomy by dangling the carrot of information obtainable by testing, and simultaneously wielding the stick of possible breaches of confidentiality, it does allow the patient to know the terms of the testing prior to the test itself and may, therefore, be in a small sense empowering. At a minimum, patients are not caught by surprise and can prevent the information from potentially being disseminated to their family members by refusing to be tested.

The other extreme from the absolutist view suggests that not only may physicians be permitted to reveal the results of genetic tests to relatives, they may have a moral imperative to do so. This position rests on two independent, although not antagonistic, assumptions. The first is that information obtained through genetic testing does not belong to the individual test subject, but rather, by its very nature, to the family.<sup>29</sup> The study of genetics—the very idea of a genetically inheritable trait—is by definition the study of families and information about those families. Thus, no issues of confidentiality really arise between tested patients and their family members. It is common information that should, and some argue must, be made available to all potentially affected family members. “Dorothy Wertz and John Fletcher suggest that it is ‘vital to recognize that hereditary information is a family possession rather than simply a personal one.’”<sup>30</sup> Therefore, when one member of the family requests genetic testing, the entire family becomes the patient to whom the professional duty of providing complete and accurate information attaches. One commentator put it this way: “Historically, the patient/physician relationship constituted a duality between a doctor and a patient with illnesses specific to that patient. Now, with the introduction of genetic mapping, however, the patient/physician relationship has been reconfigured to reflect the individual’s ties to his or her ancestors and descendants.”<sup>31</sup>

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<sup>27</sup> At least one commentator would disagree with this analysis, believing that genetic predisposition to cancer is closer to that of Huntington’s disease due to lack of a definitive treatment. See Buchanan, *supra* note 21, at 395.

<sup>28</sup> Ruth Macklin, *Privacy and Control of Genetic Information*, in GENE MAPPING: USING LAW AND ETHICS AS GUIDES 157, 164 (George J. Annas & Sherman Elias eds., 1992).

<sup>29</sup> Andrews, *supra* note 9, at 266.

<sup>30</sup> *Id.*; WERTZ, *supra* note 9; Dorothy C. Wertz & John C. Fletcher, *Privacy and Disclosure in Medical Genetics Examined in an Ethics of Care*, 5 *BIOETHICS* 212, 221 (1991). “An ethics of care would consider the patient to be the *family* at genetic risk (rather than the individual.” *Id.*

<sup>31</sup> Jeffrey W. Burnett, *A Physician’s Duty to Warn a Patient’s Relatives of a Patient’s Genetically Inheritable Disease*, 36 *HOUS. L. REV.* 559, 578 (1999).

The second premise is that public policy demands the disclosure. For public policy reasons, other exceptions have been, if not wholly accepted, at least tolerated by patients and their doctors. As previously stated, courts, legislatures, and professional mores have permitted violation of patient confidentiality when child abuse is suspected,<sup>32</sup> when a patient is the victim of a gunshot wound,<sup>33</sup> and in some states, when the patient suffers from a contagious disease that could be a public health hazard.<sup>34</sup> One may argue the differences: revelations about child abuse are designed to protect children who may otherwise have no way to protect themselves, while most (but not all) family members of genetically tested patients are adults; gunshot wound reporting serves to help law enforcement, but genetic testing involves no crime; and warning of the presence of contagious diseases involves a risk to the entire public as opposed to a single family. Nevertheless, society has yet to define the exceptions to the rule of confidentiality, and it can be argued that revealing a risk to family members could increase the general public health.

To summarize, prevailing ethical standards in the medical profession—as represented by the codes of ethics of various health care professionals—present no monolithic view on the issue of confidentiality in genetic testing. While confidentiality is important, some genetic counselors and ethicists, such as George Annas, view it as absolute.<sup>35</sup> Those at the other end of the spectrum are characterized by the work of Dorothy Wertz, which argues that genetic information belongs to families, not individuals.<sup>36</sup> Therefore, while those who subscribe to Wertz's view might object to disclosure to an outsider, such as an employer, they would not only permit the physician to warn family members, but would argue that the physician has an affirmative duty to do so. In between the extremes are those who favor a modified form of confidentiality, which begins with a presumption of confidentiality unless certain conditions are met. Some of these conditions appear to rest on the state of medical science—for example, whether treatment is available. Other conditions require a consideration of the seriousness of the harm and the identifiability of the relatives. Lastly, the ASGH requires that one who seeks to break confidentiality must balance the harm from disclosure with the harm from nondisclosure. This balancing test is a point to which I return to in the final Part of this paper.

While the foregoing is a sketch of the state of pertinent ethics codes, the question of actual practice remains. The following discussion, while not exhaustive of the literature, adds an important dimension. How do the more formal abstract codes play out in the real practice of medicine for health care professionals and patients?

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<sup>32</sup> See generally Harold Edgar & Hazel Sandomire, *Medical Privacy Issues in the Age of AIDS: Legislative Options*, 16 AM. J.L. & MED. 155 (1990).

<sup>33</sup> See *id.* at 177.

<sup>34</sup> *Id.* at 161–64.

<sup>35</sup> See, e.g., Annas, *supra* note 6.

<sup>36</sup> See Wertz & Fletcher, *supra* note 30.



Two studies attempted to determine the conditions under which medical professionals would disclose genetic testing results to relatives. The studies both involved a hypothetical in which the patient tested positive for carrying the Huntington's gene. One study involved those most protective of confidentiality—genetic counselors.<sup>37</sup> The study's results with regard to disclosure to family members at risk were as follows: 59.4% would respect the confidentiality of the patient, 19.8% would disclose if asked by relatives, and 14.5% would disclose even if not asked by relatives.<sup>38</sup>

Dorothy Wertz's earlier study of Ph.D. and M.D. counselors—who receive different training than genetic counselors<sup>39</sup>—confronted with the same scenario of a patient who refuses to warn at risk relatives, produced the following results: 39% would respect confidentiality, 29% would disclose if asked by relatives, and 24% would disclose even if not asked by relatives.<sup>40</sup>

In yet another study, physicians were asked to whom positive test results for Huntington's disease should be disclosed without the patient's permission.<sup>41</sup> Few said they would reveal the results to employers or health insurers, but many indicated that they would reveal the results to a spouse, adult children, or sibling of the patient.<sup>42</sup> This study also confirmed that physicians were most likely to reveal such information, followed by medical geneticists, while genetic counselors were least likely to breach the patient's confidentiality.<sup>43</sup> A study of general practitioners revealed that a vast majority (83%) would reveal genetic test results over the patient's objection.<sup>44</sup>

When it comes to patient expectations and beliefs, the numbers are very different from those attributed to general practitioners and medical geneticists and much closer to those associated with genetic counselors.<sup>45</sup> Of patients asked to comment on the same scenario, 65% felt that doctors should respect confidentiality, 22% felt that doctors should tell if asked by

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<sup>37</sup> Deborah F. Pencarinha, Nora K. Bell, Janice G. Edwards, & Robert G. Best, *Ethical Issues in Genetic Counseling: A Comparison of M.S. Counselor and Medical Geneticist Perspectives*, 1 J. GENETIC COUNSELING 19 (1992).

<sup>38</sup> *Id.* at 25.

<sup>39</sup> Professional genetic counselors hold masters degrees. They are not medically trained. They provide information about the genetic testing process and assist clients in decisionmaking. See Biesecker, *supra* note 7, at 113. In contrast to medical geneticists, most of whom are men, 94% of genetic counselors are women. Mary B. Mahowald, *Reproductive Genetics and Gender Justice*, in WOMEN IN PRENATAL TESTING: FACING THE CHALLENGES OF GENETIC TECHNOLOGY 67, 79 (Karen H. Rothenberg & Elizabeth J. Thomson eds., 1994).

<sup>40</sup> Pencarinha, *supra* note 37, at 25.

<sup>41</sup> Gail Geller, Ellen S. Tambor, Barbara A. Bernhardt, Gary A. Chase, Karen J. Hofman, Ruth R. Faden, & Neil A. Heltzman, *Physicians' Attitudes Toward Disclosure of Genetic Information to Third Parties*, 21 J. LAW, MED. & ETHICS 238–39 (1993)

<sup>42</sup> *Id.* at 239.

<sup>43</sup> *Id.* A survey revealed that 20.3% of physicians, 10.7% of geneticists, and 3.6% of genetic counselors would reveal results to a spouse; 28.8%, 19.0%, and 7.2% respectively, to an adult child, and 15.8%, 7.2%, and 2.9%, respectively, to a patient's sibling. *Id.*

<sup>44</sup> Pergament, *supra* note 13, at 96.

<sup>45</sup> *Id.*

relatives, and 8% felt that doctors should tell even if not asked by relatives.<sup>46</sup>

A study of a small sample of patients (forty-six women) in a genetic counseling clinic in the United Kingdom explored the question of whether and to whom the patients revealed information that they were at higher risk for breast and ovarian cancer.<sup>47</sup> Most of the women told at least one relative.<sup>48</sup> The women also acknowledged the difficulties in contacting and discussing the issue with all family members, citing practicalities such as wanting to speak face-to-face and finding it difficult to arrange.<sup>49</sup> Nearly all of the women had at least one first- or second-degree relative whom they were not intending to inform, sometimes due to a simple lack of contact with certain family members to whom they felt little, if any, connection and therefore little, if any, responsibility.<sup>50</sup>

In another, larger study involving genetic testing for breast-ovarian cancer, 57% of 238 unaffected first-degree relatives of women with breast or ovarian cancer believed that health care providers should not reveal the results of tests to family members without written consent from the patient.<sup>51</sup> While this figure was lower than that involving disclosure to employers or insurers (87%),<sup>52</sup> it nonetheless reveals that the vast majority of women desire confidentiality, even from family members.

Some studies have concentrated on how practices and expectations concerning confidentiality of genetic testing results differ across genders and cultures. Benkendorf's study revealed less concern for confidentiality among African-American women.<sup>53</sup> Another study revealed that 66% of the Caucasian women surveyed discussed genetic testing for breast cancer with a parent or spouse, while only 27% of the African-American women surveyed did.<sup>54</sup> In addition, the same study concluded that women discuss genetic testing results more than do men.<sup>55</sup> Interestingly, in Wertz and Fletcher's study of physicians' willingness to break physician-patient confidences, the age of the physician was a factor; the odds of disclosure increased by a factor of 1.9 for every ten years of age.<sup>56</sup>

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<sup>46</sup> *Id.*

<sup>47</sup> Josephine Green, Martin Richards, Frances Murton, Helen Statham, & Nina Hallowell, *Family Communication and Genetic Counseling: The Case of Hereditary Breast and Ovarian Cancer*, 16 J. GENETIC COUNSELING 45 (1997).

<sup>48</sup> *Id.*

<sup>49</sup> *Id.* at 52–53.

<sup>50</sup> *Id.*

<sup>51</sup> Judith L. Benkendorf, Jeri E. Reutenauer, Chanita Hughes, Nadine Eads, Jan Willison, Madison Powers, & Caryn Lerman, *Patients' Attitudes About Autonomy and Confidentiality in Genetic Testing for Breast-Ovarian Cancer Susceptibility*, 73 AM. J. MED. GENETICS 296, 299 (1997).

<sup>52</sup> *Id.*

<sup>53</sup> *Id.*

<sup>54</sup> Caryn Lerman, Beth N. Peshkin, Chanita Hughes, & Claudine Issacs, *Family Disclosure in Genetic Testing for Cancer Susceptibility: Determinants and Consequences*, 1 J. HEALTH CARE L. & POL'Y 353, 359 (1998).

<sup>55</sup> *Id.* at 358–59.

<sup>56</sup> Dorothy C. Wertz & John C. Fletcher, *Ethics and Medical Genetics in the United States: A National Survey*, 29 AM. J. MED. GENETICS 815, 820 (1988).

The existing studies have demonstrated that patient expectation of confidentiality is the norm, and, except for the discreet group of recently-trained genetic counselors, physician expectation of privacy is decidedly far from the norm. Patients who assume that their doctors will keep their secrets, particularly genetic testing results, are more likely relying on their own perspectives and wishes and remain ignorant of their doctors' professional ethics and personal behavior regarding the matter.

### III. THE LEGAL LANDSCAPE

As of the writing of this Article, there exists no federal legislation that squarely addresses the issue of to whom genetic test results may be revealed. The Department of Health and Human Services has recently issued final regulations known as the "Standards for Privacy of Individually Identifiable Health Information."<sup>57</sup> The impetus for their creation appears to be the growing unease among individuals over a lack of standards and the consequent fear that public entities, such as insurance companies and employers, may obtain damaging information about patients without their knowledge or consent. These anxieties have been fueled by recent advancements in electronic technology, involvement of greater numbers of health care professionals in an individual's health care, and interest in patient information from the scientific research community,<sup>58</sup> all of which exponentially increase the risk of disclosure.

The effect of these standards, which are still being digested by the health care industry, health care professionals, and the public, remains unclear. To the extent that the standards address communications between doctors and family members, patient consent requirements are weak, requiring at best oral, not written, consent; and in some cases, consent can be implied.<sup>59</sup> Moreover, when it comes to speaking with family members, this section of the standards accords much deference to a physician's "professional judgment."<sup>60</sup> For example, in the preamble, there is much discussion about seeking balance between individual needs for privacy and competing, sometimes social, goals. The authors state, "Neither privacy, nor the important social goals described by the commenters, are absolutes."<sup>61</sup> Later, they acknowledge the important role that standards and practices of professional organizations will continue to play, and they quote the current American Medical Association's stance as: "conflicts between a patient's right to privacy and a third party's need to know should be resolved in favor of the patient, except where that would result in serious health hazard or harm to the patient or others."<sup>62</sup> Another section appears to

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<sup>57</sup> Standards for Privacy of Individually Identifiable Health Information: Final Rule, 65 Fed. Reg. 82462-82829 (Dec. 28, 2000) (to be codified at 45 C.F.R. pts. 160 & 164) [hereinafter Standards].

<sup>58</sup> *Id.* at 82463.

<sup>59</sup> *Id.* at 82522 (§ 164.510(b)).

<sup>60</sup> *Id.*

<sup>61</sup> *Id.* at 82471.

<sup>62</sup> *Id.* at 82472.

allow disclosure in Tarasoff-type situations,<sup>63</sup> where permitting such disclosure would avert serious danger to health and safety. Thus, the debate about what constitutes harm and which specific instances can trigger disclosure remains; in this regard, these regulations appear to adopt the current muddy standards of practice, not to clarify them.

Further analysis of these standards is beyond the scope of this Article. The attention paid thus far by the health care industry and others has raised, rather than answered, questions, and in the period set for compliance (two or three years, depending on the size of the covered entity), clarity will be called for and may eventually ensue. At the moment, however, these standards do not focus on genetic information, and speak only tangentially on physician-family communications. What one is able to glean from indirect treatment of the issue is that these standards will have little effect upon the present practice regarding disclosure of genetic information to family members.

States, on the other hand, have grappled with the issues of genetic testing and privacy in typical patchwork fashion, providing varying degrees of privacy protection.<sup>64</sup> At least one legal commentator has addressed this issue by placing it in the broader legal context of the “duty to rescue” doctrine.<sup>65</sup> Lori B. Andrews notes that geneticists, who seem to have some propensity for informing relatives against a patient’s wishes:

may be surprised at how little regard the law has for the plight of a third party absent a contractual duty or an action on the part of the person that actually causes harm to the third party. It is a well-known legal adage that there is no “duty to rescue.” A person who walks past someone else’s child drowning in a wading pool has no legal responsibility to save that child, even if it could easily be accomplished without risk to the rescuer.<sup>66</sup>

A real-life and undeniably shocking example is that involving the murder of Sherrice Iverson by Jeremy Strohmeier in a Las Vegas casino women’s restroom. David Cash, a friend and companion of the murderer, not only fled the scene when he reasonably expected that the killing was taking place, he took absolutely no action that might have prevented the murder.<sup>67</sup> While David Cash has been thought to have engaged in morally degenerate behavior, the law could not impose any criminal sanction upon him, precisely because he was under no legal duty to “rescue” the victim.

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<sup>63</sup> *Id.* at 82538. For discussion of the relation of *Tarasoff* to the subject of this Article, see notes 70–74 and accompanying text.

<sup>64</sup> See generally Marc Rotenberg, *Institute of Medicine, Health Data in the Information Age: Use, Disclosure, and Privacy*, Electronic Privacy Information Center, at <http://www.epic.org/privacy/medical/journal.txt> (Spring 1995) (discussing briefly the relative merits of federal and state legislation in this area).

<sup>65</sup> See RESTATEMENT (SECOND) OF TORTS § 314 (1965).

<sup>66</sup> Andrews, *supra* note 9, at 266.

<sup>67</sup> This case resulted in over 300 newspaper accounts nationwide, and is often referred to as “the David Cash case.” Kathleen Ridolfi, *Law, Ethics, and the Good Samaritan: Should There Be a Duty to Rescue?*, 40 SANTA CLARA L. REV. 957, 968 (2000). See generally Alison M. Arcuri, *Sherrice Iverson Act: Duty to Report Child Abuse and Neglect*, 20 PACE L. REV. 471 (2000) (further discussing the “no duty to rescue” doctrine in that case); Andrew D. Kaplan, “Cash-ing Out:” *Regulating Omissions, Analysis of the Sherrice Iverson Act*, 26 NEW ENG. J. ON CRIM. & CIV. CONFINEMENT 67 (2000) (further discussing the “no duty to rescue” doctrine in that case).

Similarly, bystanders who failed to help Kitty Genovese as she was being murdered in New York City have been criticized for their moral failure, but nothing in the law could support a finding that they had a legally enforceable duty to act.

Although, admittedly, it is a leap to analogize murder witnesses to doctors in possession of genetic testing results, the comparison is apt. While some doctors may believe that they must inform relatives of potential harm, the law is not likely to demand that doctors do so. The “no duty to rescue” doctrine would impose no affirmative duty on doctors to ameliorate risks to third parties.<sup>68</sup>

For the most part, courts have been spared the thorny issue of whether physicians have a legal duty to warn relatives of the results of genetic testing over the objections of a patient. Two cases have come to opposite conclusions. The first, *Pate v. Threlkel*, questioned whether a physician was required to warn a patient’s relatives that she suffered from cancer of the thyroid and that the family might also be at risk.<sup>69</sup> The court concluded that the doctor should have recognized the risk to family members, but stated:

Our holding should not be read to require the physician to warn the patient’s children of the disease. In most instances the physician is prohibited from disclosing the patient’s medical condition to others except with the patient’s permission. . . . To require the physician to seek out and warn various members of the patient’s family would often be difficult or impractical and would place too heavy a burden upon the physician. Thus, we emphasize that in any circumstances in which the physician has a duty to warn of a genetically transferable disease, that duty will be satisfied by warning the patient.<sup>70</sup>

A New Jersey appellate court found differently.<sup>71</sup> In *Safer v. Pack*, an adult daughter, upon discovering that she had colon cancer, learned that her father had died from the same disease many years before. After investigating her father’s medical records, she claimed that the type of cancer had a genetic component, and that her father’s doctor should have warned her that she was at risk. She sued the estate of the deceased physician, and due to problems of proof,<sup>72</sup> she lost the suit. The court,

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<sup>68</sup> A counterargument might center on the fact that the “no duty to rescue” doctrine is inapplicable if a “special relationship” exists between the parties. For example, one would, as a parent, have a duty to rescue one’s own child. Special relationships listed in the *Restatement (Second) of Torts* include common carriers, passengers, innkeepers, and guests. RESTATEMENT (SECOND) OF TORTS § 314 (1965). Exactly what constitutes a “special relationship” is difficult to determine. It seems a stretch to say that physicians have a “special relationship” with a patient’s family members, many of whom they have probably never met. Thus, there is probably no exception to the “no duty to rescue” doctrine for physicians.

<sup>69</sup> *Pate v. Threlkel*, 661 So. 2d 278 (Fla. 1995).

<sup>70</sup> *Id.* at 282.

<sup>71</sup> 677 A.2d 1188 (N.J. Super. Ct. App. Div. 1996).

<sup>72</sup> For example, the plaintiff was not able to clearly show that the doctor had failed to warn her. There was evidence that she had undergone certain medical examinations as a child that she would not otherwise have been subjected to if her mother had been informed of the genetic connection and risk. The fact that two of the plaintiff’s witnesses, her father and the doctor, were dead, and that the plaintiff had to rely on old medical records may have made it difficult for her to prove the factual basis to support her claim. *Id.* at 1192–93.

however, viewed the risk from genetic disease to be “by definition a matter of familial concern,” and stated:

Further, it is appropriate . . . that the duty be seen as owed not only to the patient himself but that it also ‘extend[s] beyond the interests of a patient to members of the immediate family of the patient who may be adversely affected by a breach of that duty.’<sup>73</sup>

Recognizing that it was treading on controversial ethical and legal grounds, the court went on to say that important policy considerations were at stake, especially when patients expressly forbid their doctors to disclose information to family members.<sup>74</sup> Assuming that such a prohibition by the patient could be proven, the court specifically rejected the holding and reasoning of *Pate v. Threlkel* stating, “[T]he court will be required to determine whether, as a matter of law, there are or ought to be any limits on physician-patient confidentiality, especially after the patient’s death where a risk of harm survives the patient, as in the case of genetic consequences.”<sup>75</sup>

Thus, while the plaintiff in *Safer* failed to prove the elements of her claim, it is clear that the New Jersey court believed that physicians could violate their patient’s wishes for confidentiality and advise family members of the patient’s condition and the consequent risks to relatives.

Despite the fact that it does not concern genetic disease, *Tarasoff v. The University of California Regents*, deserves mention.<sup>76</sup> *Tarasoff* involved a University-employed psychiatrist in whom a patient had confided his desire to kill an acquaintance. The psychiatrist attempted to solicit the help of the university administration but did not directly contact the young woman who was the object of the threat, nor her parents. When the patient carried out the threat and murdered the young woman, her parents sued the university. The court held that the psychiatrist had a duty to notify the young woman about the threats and justified the breach of patient confidentiality on the public policy ground that preventing murder was a more important social objective.<sup>77</sup>

What do these three cases mean for the issue at hand? While little case law exists, at least two of the three cases have opened the door not only for justifying breaches of patient confidentiality, but also for imposing a duty on a physician to do so. Clearly, *Safer* is more on point than *Tarasoff*, and some commentators have dismissed *Tarasoff*’s relevance to the situation presented by genetic testing.<sup>78</sup> Yet, *Tarasoff* is ever present in the discussion, probably because the idea of “public policy considerations” is such a malleable concept. Even though, as Ellen Clayton and others have argued, there is a difference between failing to warn about threats of

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<sup>73</sup> *Id.* at 1192.

<sup>74</sup> *Id.*

<sup>75</sup> *Id.* at 1193.

<sup>76</sup> 551 P.2d 334 (Cal. 1976).

<sup>77</sup> *Id.* at 344–48.

<sup>78</sup> See, e.g., INST. OF MED., *supra* note 17, at 256–58; Ellen Wright Clayton, *What Should the Law Say About Disclosure of Genetic Information to Relatives*, 1 J. HEALTH CARE L. & POL’Y 373, 387 (1998). *But see* Burnett, *supra* note 31, at 563–65.

violence and failing to warn of genetic risks,<sup>79</sup> the difference is neither so self-evident nor so clearly articulated. Indeed, it may be that there is a cumulative effect when public policy is invoked, such that each exception in the name of public policy gives credence to the next one proposed. Health, although highly personal, has a public component that goes beyond the traditional concern with contagious diseases. Health and health care have become public issues as society debates how best to provide for the health and medical treatment of its citizens. Surely, particularly where early treatment is available, one can foresee the arguments about how the public interest is enhanced if relatives are informed of a patient's test results so that they too may obtain early treatment—and by implication, less expensive treatment in the long run. Thus, the “no duty to rescue” doctrine<sup>80</sup> could give way to the “public health model,” which enlists physicians as major players and places upon them affirmative duties of revealing information.

#### IV. WHY WOMEN ARE DIFFERENT

There are several reasons why all individuals should be concerned about privacy and genetic testing, but there are some reasons that may be of particular concern to women. These include the threat of domestic violence and loss of employment or change in employment conditions, if the definition of employment can be expanded to include work within the home. Before a discussion of each of these, it is necessary to state the near-obvious: any information that is disclosed by a physician to even a single family member is information over which the patient has lost control.<sup>81</sup> A secret-holder is a potential secret-teller. Regardless of how careful and judicious a health care provider may be in limiting disclosure to only those family members for whom the information is most pertinent, a disclosure to one is a potential and, in many cases, actual disclosure to all. One family member may tell others, who may repeat the information to yet other relatives. Nor is the expansion in the number of secret-holders limited to family members. Particularly in small communities, the lines between family, friend, neighbor, and outside employer are tenuous. A family member shares the secret with a coworker, who may be a friend of someone who shares the same employer as the patient. These “six (or fewer) degrees of separation” relationships are common in small towns, rural areas, and even within some professional spheres. This observation is relevant as we move on to a discussion of domestic violence, most often perpetrated against women by their husbands or intimate partners who are not

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<sup>79</sup> Andrews, *supra* note 9, at 255–57; Macklin, *supra* note 28, at 162–64.

<sup>80</sup> See RESTATEMENT (SECOND) OF TORTS § 314 (1965).

<sup>81</sup> This is an issue that has been recognized in conjunction with partner or contact notification of HIV status. Under many current laws, partners have no obligation to keep HIV-related information about the person who infected him or her confidential. Matthew Carmody, *Mandatory HIV Partner Notification: Efficacy, Legality, and Notions of Traditional Public Health*, 4 TEX. F. ON C.L. & C.R. 107, 113 (1999). Moreover, it would be difficult if not impossible to enforce a law that prohibited disclosure by the partner or contact. Sonia Bhatnager, *HIV Name Reporting and Partner Notification in New York State*, 26 FORDHAM URB. L.J. 1457, 1477 (1999).

genetically related to the woman and therefore not necessarily within the ambit of “family” for purposes of disclosure of genetic information. Being genetically unrelated, husbands and intimate partners may not be on the list of family members to whom disclosures would be made by the health care provider, but it is not unlikely that other family members who possess the secret would share it with them.

#### A. THE THREAT OF DOMESTIC VIOLENCE

Despite all of the attention paid to domestic violence in the last twenty or more years, it remains a dominant feature in the lives of women. The most recent and comprehensive study of the prevalence of domestic violence found that 52% of women in the United States had been physically assaulted during their childhood and/or adulthood.<sup>82</sup> The study estimates that 1.9 million women are assaulted each year in the United States.<sup>83</sup> Moreover, women experience significantly more partner violence than men do. Compared to 8% of men, 25% of women (which coincides with the steady figure over the years of one in four) said that they had been raped and/or physically assaulted by a male partner in their lifetime.<sup>84</sup> Seventy-six percent of all assaults upon women were committed by a male partner, as opposed to 17.9% for men.<sup>85</sup> Furthermore, women who are assaulted are more likely to be seriously injured than men.<sup>86</sup>

It is an understatement to say that the threat and the occurrence of domestic violence is complex. Scholars from many disciplines have attempted to answer the question of why domestic violence occurs. There are political theories highlighting no particular factors, suggesting that the attempt to identify factors that might precipitate domestic violence denies a simpler truth—that the battering of women (which constitutes the vast majority of battering in households) is done by men because they can. Some psychological theories state that batterers use violence as a means of exercising control and thereby derive the psychological benefit that controlling another human being supposedly gives.<sup>87</sup> Other theorists have conducted research seeking to determine whether certain factors give rise to battering or, as actual causal connections are often scientifically questionable, whether there are correlations between certain factors and the presence of domestic violence in a relationship.<sup>88</sup> Future studies should consider exploring the issue of whether the revelation that a woman is carrying the gene for breast cancer or for Huntington’s disease, as examples, would increase her chances of experiencing domestic violence.

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<sup>82</sup> PATRICIA TJADEN & NANCY THEONNES, NAT’L INST. OF JUST. CTRS. FOR DISEASE CONTROL AND PREVENTION, U.S. DEP’T OF JUSTICE, PREVALENCE, INCIDENCE, AND CONSEQUENCES OF VIOLENCE AGAINST WOMEN 5 (1998) (reporting on the National Violence Against Women survey conducted jointly by the U.S. Department of Justice’s National Institute of Justice and Centers for Disease Control and Prevention).

<sup>83</sup> *Id.*

<sup>84</sup> *Id.*

<sup>85</sup> *Id.*

<sup>86</sup> *Id.*

<sup>87</sup> See generally, DONALD G. DUTTON, THE BATTERER: A PSYCHOLOGICAL PROFILE (1995).

<sup>88</sup> See *infra* notes 89–121 and accompanying text.



Because no studies bear directly on the correlation, if any, between genetic testing and domestic violence, we must look at work that has been done in what might be corollary areas. Some of the studies that may be germane to this question involve other medical conditions, including pregnancy, HIV status, and cancer. The following discussion is not exhaustive of the research in any of these areas nor is it meant to be. It may, however, cause us to draw some parallels between each of these factors and genetic predispositions, and to ask the question: Does conveying information about a woman's genetic predisposition to family members increase the risk of domestic violence?

Studies linking pregnancy and domestic violence stand in stark contrast to the comforting image of the family—particularly marriage or marriage-like relationships—as benign. One survey of thirteen studies on this issue revealed that the prevalence of violence during pregnancy ranged from 0.9%–20.1%,<sup>89</sup> and concluded that “[v]iolence may be a more common problem for pregnant women than conditions for which they are routinely screened and evaluated.”<sup>90</sup> Another survey of four studies estimated prevalence to range from 4%–24%, with higher numbers recorded when the subject is asked about violence at more than one point during prenatal care and when the questions came from a health care provider rather than an anonymous questionnaire.<sup>91</sup>

It is true that many confounding factors make the correlation between domestic violence and pregnancy a muddy one. One study, for example, revealed that pregnant women do get beaten, but that age is another variable, with 28.9% of pregnant women under the age of twenty-five reporting violence as compared to 11.2% of those twenty-five years and older reporting the same.<sup>92</sup> Several studies have attempted to refine the factors by examining whether the pregnancy was intended. One study documented that rates of unintended pregnancies (defined as occurring sooner than desired or unwanted at any time) were 35% for married women and 65% for single women.<sup>93</sup> The authors of the study then concluded that women with unwanted pregnancies reported higher rates of violence, approximately 4.1 times that of women with intended pregnancies.<sup>94</sup> Moreover, unwanted pregnancies accounted for 70% of women who reported physical violence.<sup>95</sup> The authors also cite a recent Canadian study that coincided with their own findings.<sup>96</sup>

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<sup>89</sup> Julie A. Gazmarian, S. Lazorick, A.M. Spitz, T.J. Ballard, L.E. Saltzman, & J.S. Marks, *Prevalence of Violence Against Pregnant Women*, 24 JAMA 1915, 1918 (1996).

<sup>90</sup> *Id.* See also Julie A. Gazmarian, Melissa M. Adams, Linden E. Saltzman, Christopher H. Johnson, F. Carol Bruce, James S. Marks, S. Christine Zahniser, & Prams Working Group, *The Relationship Between Pregnancy Intendedness and Physical Violence in Mothers of Newborns*, 85 OBSTETRICS & GYNECOLOGY 1031, 1031 (1995). “[V]iolence during pregnancy is more common than placenta previa, preeclampsia, or gestational diabetes.” *Id.*

<sup>91</sup> Gigi Evins & Nancy Chescheir, *Prevalence of Domestic Violence Among Women Seeking Abortion Services*, 6 WOMEN'S HEALTH ISSUES 204, 207 (1996).

<sup>92</sup> Gazmarian et al., *supra* note 90, at 1031 (citing The Second National Family Violence Survey).

<sup>93</sup> *Id.* at 1032.

<sup>94</sup> *Id.* at 1035.

<sup>95</sup> *Id.* at 1034.

<sup>96</sup> *Id.* at 1036.

It appears that the only clear thing we know about the link between pregnancy and violence is that a causal relationship is far from clear.<sup>97</sup> We do know, however, that research shows that pregnancy, especially an unintended or unwanted pregnancy, results in higher reported incidences of physical abuse of women by a husband or partner.

Finally, the most recent study—one originally designed to measure something else entirely—is sadly illuminating in its unexpected result. Two researchers sought to determine the causes of pregnancy-associated death in women, which was defined as death from any cause during pregnancy or within one year of delivery or pregnancy termination.<sup>98</sup> Of the 247 deaths investigated, homicide was the leading cause of death, accounting for the deaths of fifty of the women.<sup>99</sup> This number of pregnant women who were murdered exceeded the numbers of those who died as a result of more common medical problems, such as cardiovascular disorders, embolisms, accidents, hemorrhage, hypertension disorders, infections, and suicide.<sup>100</sup>

Another parallel may be found in studies about revealing HIV status to a partner. Many states have required that partners and former partners be notified of a patient's HIV status as a public health measure—and to warn the individual partners that they should be tested and, if found positive, treated. Some studies have looked at the correlation of revealing HIV status to increases in domestic violence. These studies have resulted in the recognition that physical harm to a patient by a partner is one of the main potential harms in partner notification programs.<sup>101</sup> One study of nearly 3000 HIV-infected adults, showed that, overall, 20.5% of women, 11.5% of homosexual men, and 7.5% of heterosexual men reported physical harm by a partner or significant other, and that nearly half reported that their HIV positive status was the cause of the violence.<sup>102</sup> Women living with a male versus a female partner were three times as likely to report violence in conjunction with their diagnosis.<sup>103</sup> An earlier study of 136 health care providers for HIV-infected women showed similar findings.<sup>104</sup> Forty-five percent of the providers had one or more patients who expressed a fear of

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<sup>97</sup> See generally RUTH PETERSEN, LINDA E. SALTZMAN, MARY GOODWIN, & ALISON SPITZ, CTRES. FOR DISEASE CONTROL AND PREVENTION, KEY SCIENTIFIC ISSUES FOR RESEARCH ON VIOLENCE OCCURRING AROUND THE TIME OF PREGNANCY (1998) (suggesting issues for further research).

<sup>98</sup> Isabelle L. Horon & Diana Cheng, *Enhanced Surveillance for Pregnancy-Associated Mortality—Maryland, 1993–1998*, 285 JAMA 1455, 1455 (2001).

<sup>99</sup> *Id.* at 1457.

<sup>100</sup> *Id.*

<sup>101</sup> Andrea Carlson Gielen, Patrizia O'Campo, Ruth R. Faden, & Agatha Eke, *Women's Disclosure of HIV Status: Experiences of Mistreatment and Violence in an Urban Setting*, 25 WOMEN & HEALTH 19, 30 (1997).

<sup>102</sup> Sally Zierler, William E. Cunningham, Ron Anderson, Martin F. Shapiro, Sam A. Bozzette, Terry Nakazono, Sally Moston, Stephan Crystal, Michael Stein, Barbara Turner, & Patti St. Clair, *Violence Victimization After HIV Infection in a US Probability Sample of Adult Patients in Primary Care*, 90 AM. J. PUB. HEALTH 208, 211 (2000).

<sup>103</sup> *Id.*

<sup>104</sup> Karen H. Rothenberg & Stephen J. Paskey, *The Risk of Domestic Violence and Women with HIV Infection: Implications for Partner Notification, Public Policy, and the Law*, 85 AM. J. PUB. HEALTH 1569 (1995).

physical violence due to disclosure of their HIV status.<sup>105</sup> The providers reported that:

Patients were kicked, beaten, shot and raped and suffered knife wounds to the face. One patient broke both legs after jumping from a third-floor window to escape being shot. The incidents of emotional abuse ranged from partners spitting on patients to threats of violence and death against both the women and their children. Some of these incidents occurred in the presence of providers.<sup>106</sup>

Rothenberg and Paskey concluded that partner notification of HIV status should not occur unless and until HIV-infected women are screened for risk of domestic violence.<sup>107</sup> Another study of fifty HIV-positive women echoed these findings, with one-quarter of the sample reporting negative consequences of disclosure, including physical assault.<sup>108</sup> Threats of violence were also present. One woman described her male partner's behavior as follows: "One day, he kicked the TV . . . and knocked up all the furniture, and took soap and wrote 'AIDS b[itch]' on the mirror."<sup>109</sup> The tension between the world of the medical establishment and the reality of one woman's life is palpable in her words: "They (the clinic) want me to come out and tell him. I keep trying to tell them, 'I'll send him down here let y'all tell him. Don't say my name, cause that man is violent.'"<sup>110</sup> The authors of this study acknowledge that many negative reactions to HIV disclosures may be predicated on public ignorance,<sup>111</sup> and hiding HIV status may only contribute to that ignorance. Nevertheless, as the authors conclude, "the burden of educating 'the public' . . . should not fall to the women themselves."<sup>112</sup>

Other health crises in the lives of women may also provide additional parallels. These studies do not measure domestic violence per se, but try to assess the stress levels of patients and their partners associated with various diseases. To the extent that stress is a catalyst to acts of domestic violence, these studies are relevant. Several of these studies have tried to demonstrate how the presence of cancer, as well as other disorders, in a family affects family functioning. Several of these studies have tried to sort out whether gender differences exist. Some have dealt with the effect of breast cancer on patients and their husbands or partners. Others have tried to measure the effects of colon cancer on male and female patients and their families. Still others have looked at families' reactions to substance abuse treatment and dialysis.

As for the breast cancer studies, results and conclusions were varied. Not all subjects in every study showed disproportionate negative effects on family functioning. It is fair to say, however, that a significant number of

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<sup>105</sup> *Id.* at 1570.

<sup>106</sup> *Id.* (citing their earlier study, found at 50 J. AM. MED. WOM. ASS'N 87-93 (1995)).

<sup>107</sup> *Id.* at 1573.

<sup>108</sup> Gielen et al, *supra* note 101, at 19.

<sup>109</sup> *Id.* at 27.

<sup>110</sup> *Id.* at 26.

<sup>111</sup> *Id.* at 30.

<sup>112</sup> *Id.*

subjects in several different studies reported that having breast cancer strained family relationships. For example, one study revealed that patients with breast cancer evinced higher levels of depressed mood, which in turn had a negative effect on their marriages.<sup>113</sup> Another study hypothesized that while breast cancer alone did not always cause marital stress, it contributed to it when other stressors were present.<sup>114</sup> Yet another study, which examined adjustments of patients and spouses over time, revealed that husbands experienced stress that was more severe than that of the patient-wives, and that the stress lasted well beyond the treatment period itself due to lingering fear of the spread of the cancer.<sup>115</sup>

Two colon cancer studies are revealing. As one study stated, the incidence of colon cancer is fairly evenly distributed between men and women, making it easier to study the effect of gender in care-taking roles. That study revealed that, while both men and women acted in care-giving capacities, women caregivers (wives) spent twice as many hours in care-taking activities than did male caregivers (husbands).<sup>116</sup> Another echoed the findings of the Gilbar breast cancer study, reporting that husbands of female colon cancer patients evinced more symptoms of psychological stress than their patient-wives, and in many instances even more than the male colon cancer patients.<sup>117</sup>

Finally, three other studies provide further insight. One study dealing with dialysis treatment challenged the assumption that spouses should be counted on to provide support to patients because they are too distressed themselves to function in the support role—this was more true for husbands than for wives.<sup>118</sup> Another study concerning substance abuse treatment was even more to the point. It found that support from family is crucial to the patient's recovery, but that such an assumption has been based on the study of male substance abusers and their female spouses or partners.<sup>119</sup> In this study, husbands were found to be poor support givers, so much so that the suggested protocol in the case of married female substance abusers was to look for others, rather than the husband, to support her.<sup>120</sup> Another study acknowledged that the gender differences in the social and family problems

<sup>113</sup> Frances Marcus Lewis, Mary A. Hammond, & Nancy F. Woods, *The Family's Functioning with Newly Diagnosed Breast Cancer in the Mother: The Development of an Explanatory Model*, 16 J. BEHAV. MED. 351, 363 (1993).

<sup>114</sup> Laurel Northouse, *A Longitudinal Study of the Adjustment of Patients and Husbands to Breast Cancer*, 16 ONCOLOGY NURSING F. 511, 515 (1989).

<sup>115</sup> Ora Gilbar, Mariana Steiner, & Jack Atad, *Adjustment of Married Couples and Unmarried Women to Gynecological Cancer*, 4 PSYCHO-ONCOLOGY 203, 210 (1995).

<sup>116</sup> Laurel L. Northouse, Darlene Mood, Thomas Templin, Suzanne Mellon, & Tamara George, *Couples' Patterns of Adjustment to Colon Cancer*, 50 SOC. SCI. & MED. 271, 281 (2000) (citing a study by S.M. Allen, *Gender Differences in Spousal Care Giving and Unmet Need for Care*, 49 J. GERONTOLOGY S187–S195 (1994)). For an excellent summary of studies on gender and care-taking roles, see Susan M. Allen, Frances Goldscheider, Desirée A. Ciambone, *Gender roles, Marital Intimacy and Nomination of Spouse As Primary Caregiver*, 39 GERONTOLOGIST 150–58 (1999).

<sup>117</sup> Lea Baider & Atara Kaplan De-Nour, *Adjustment to Cancer: Who Is the Patient—The Husband or the Wife?*, 24 ISR. J. MED. SCI. 631, 635 (1988).

<sup>118</sup> Varda Soskolne & Atara Kaplan De-Nour, *The Psychosocial Adjustment of Patients and Spouses to Dialysis Treatment*, 29 SOC. SCI. & MED. 497, 501 (1989).

<sup>119</sup> Thomas G. Brown, Morris Kokin, Peter Seraganian, & Norman Shields, *The Role of Spouses of Substance Abusers in Treatment: Gender Differences*, 27 J. PSYCHOACTIVE DRUGS 223, 223–24 (1995).

<sup>120</sup> See *id.* at 228.

of substance abusers are not always clear, but did find that female substance abusers tend to have fewer significant others on whom they can rely for support.<sup>121</sup>

It is impossible to determine with any certainty the effects on a woman of the disclosure of her genetic condition to family members, particularly to spouses or partners. While the above examples of pregnancy, cancer, and other illnesses are not perfect parallels to the “mere” presence of a condition that may or may not ever express itself, they do provide evidence that must be examined when considering the potential threat to women in these circumstances. The prevalence of domestic violence and its admittedly tenuous relationship to pregnancy and HIV status, or even the arguably less dramatic change in family dynamics and lack of emotional support brought about by a woman’s illness, should be sufficient to invoke at least a long pause in our consideration of disclosure to family members.

#### B. LOSS OF EMPLOYMENT

The single issue that appears to be the most male-oriented in the discourse about the problems associated with privacy of genetic and medical information is the separation between the concepts of “employer” and “family.” Virtually every discussion of the issue is divided in this way. Should an employer have access to the results of genetic testing? Should the family? In a Venn diagram, the two would be represented as two completely separate circles. For women, however, the circles may be overlapping, and, in some cases, constitute the same circle.

The threat of having an employer know the results of an employee’s genetic test has been viewed primarily in economic terms. The fear is one of employment discrimination, in its most extreme form—that one will lose one’s job or that the conditions of the job will change in some way that is injurious to the worker. Women who work outside the home undoubtedly share these fears with men, and women are working outside of the home in record numbers. In the United States, approximately 60% of women over the age of sixteen are in the labor force, comprising 46% of all labor force participants.<sup>122</sup> Yet 25% of women workers are employed part-, not full-time, and women comprise nearly 40% of “contingent” workers—defined as workers who do not perceive themselves as having an explicit contract for continued employment, such as temporary help agency workers, part-time, and seasonal workers.<sup>123</sup> The prominent disparity between men’s and women’s wages remains; women earn only 76% of what men earn.<sup>124</sup>

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<sup>121</sup> Diane Rae Davis & Diana M. DiNitto, *Gender Differences in Social and Psychological Problems of Substance Abusers: A Comparison to Nonsubstance Abusers*, 28 J. PSYCHOACTIVE DRUGS 135, 142–43 (1996). See also Edith S. Lisansky Gomberg, *Facts on: Women and Alcohol*, at <http://www.rci.Rutgers.edu/~cas2/facts.html> (last visited Nov. 20, 2001) (stating that marital disruption is more likely for female than male substance abusers).

<sup>122</sup> WOMAN’S BUREAU, U.S. DEP’T OF LABOR, FACTS ON WORKING WOMEN (Mar. 2000), [http://www.dol.gov/dol/wb/public/wb\\_pubs/20fact00.htm](http://www.dol.gov/dol/wb/public/wb_pubs/20fact00.htm).

<sup>123</sup> *Id.*

<sup>124</sup> *Id.*

Women are more likely to be part-time workers who have less access than other workers to traditional fringe benefits such as health insurance.<sup>125</sup>

Despite their considerable workforce participation, many women are still economically dependent upon marriage partners. One commentator states:

Whether because of sex discrimination, the division of marital responsibilities, or individual differences in ability, ambition, education, training, or social encouragement, husbands are likely to earn more than their working wives. For their part, women continue to assume a large share of the family's domestic responsibilities, a share compounded with the arrival of children. The longer the marriage, the more likely even working women are to be dependent on their husband's income to maintain their standard of living, the more likely they are to have sacrificed to some degree their own financial future to further the marriage . . . .<sup>126</sup>

This continued disparity is echoed in the studies that have charted the relative economic conditions of men and women after divorce, showing that women are left in worse financial condition (compared to their spouses, and their own condition while married) when their marriages dissolve.<sup>127</sup> If we view employment primarily in economic terms, as a means to obtain resources, marriage and employment are not separate for women; rather, for many women, marriage is employment.

If individuals fear that a genetic condition may lead to loss of a job, women in particular may fear that it may lead to loss of marriage and, consequently, loss of access to income and other resources such as health insurance.<sup>128</sup> The *Guidelines on Ethical Issues in Medical Genetics* has recognized that disclosure of the results of genetic testing may impact men and women differently in precisely this way:

Some parties are especially vulnerable and therefore need special consideration. Women usually have less favourable [sic] access to economic resources than do men (United Nations, 1991). Women may

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<sup>125</sup> See JAMES T. BOND, ELLEN GALINSKY, & JENNIFER E. SWANBERG, FAMILIES AND WORK INSTITUTE, THE 1997 NATIONAL STUDY OF THE CHANGING WORKFORCE, EXECUTIVE SUMMARY, at <http://ilswwww.igc.apc.org/fwi/pubs/nscw.pdf> (last visited Nov. 20, 2001). See also WILLIAM S. CUSTER & PAT KETSCHKE, HEALTH INS. ASS'N OF AM., EMPLOYMENT-BASED HEALTH INSURANCE COVERAGE (2000), available at <http://membership.hiaa.org/pdfs/001211CusterStudy.pdf>.

<sup>126</sup> Margaret Brinig & June Carbone, *The Reliance Interest in Marriage and Divorce*, 62 TUL. L. REV. 855, 869 (1988).

<sup>127</sup> LENORE J. WEITZMAN, THE DIVORCE REVOLUTION: THE UNEXPECTED SOCIAL AND ECONOMIC CONSEQUENCES FOR WOMEN AND CHILDREN IN AMERICA 323-56 (1985). While there have been some critics of Weitzman's original interpretation of data, her basic premises remain true. See, e.g., S.M. Bianchi, Lekha Subaiya, & Joan R. Kahn, *The Gender Gap in the Economic Well-Being of Nonresident Fathers and Custodial Mothers*, 36 DEMOGRAPHY 195, 195-202 (1999).

<sup>128</sup> The economic importance of employer-provided health insurance cannot be overestimated. Loss of a job and attendant health insurance benefits may require women to seek private insurance as individuals, who "will probably end up having to pay a lot more money' for health insurance if they test positive for a cancer gene." Gina Kolata, *Advent of Testing for Breast Cancer Genes Leads to Fears of Disclosure and Discrimination*, N.Y. TIMES ON THE WEB, at <http://www.nytimes.com> (Feb. 4, 1997) (quoting Richard Coorsh, spokesperson for the Health Insurance Association of America).

therefore suffer more than men from the effects of some decisions or disclosures, because they must depend upon the family unit for support.<sup>129</sup>

It is not difficult to imagine the reasons why women might fear abandonment by their husbands under these circumstances. The presence of a genetic condition may induce emotional responses that place the marriage under stress. Should the genetic condition be one that might influence reproductive decisions, women may feel that husbands will look to other, “genetically superior” women with whom to father children. There is little in the way of empirical evidence on this point, and again, what evidence exists is drawn from the analogous situations of women with breast cancer. One Canadian study tried to examine a common belief that husbands desert wives who have breast cancer.<sup>130</sup> Despite the common wisdom, the study found that “marital breakdown was never higher in women with breast cancer than in control women,” and concluded that, where divorce occurred, it was probably among those women who had marital difficulties when diagnosed.<sup>131</sup> And yet, one anecdotal piece of information from a renowned and experienced physician would suggest otherwise. Larry Norton, M.D., director of the Evelyn Lauder Breast Cancer Center at Sloan-Kettering Memorial in New York City, appeared on *Larry King Live* in a program on breast cancer. What follows is taken from a transcript of the show:

King: Doctor, do you talk today to the husband?

Norton: Of course, yes. The whole family is involved right from the beginning.

King: Do you still have husbands who, frankly, turn off from it?

Norton: Yes.

King: Divorce?

Norton: Yes, yes, yes, we see men leave their sick wives. We do. It’s heartbreaking. I’ve never seen a woman leave a sick husband, though.

King: That’s interesting.

Norton: It’s very interesting.

King: In your whole career in oncology?

Norton: That’s right.

King: A man diagnosed with cancer did have a woman walk out.

Norton: I have never once seen a woman leave a sick man, but I do see men leave sick wives. We do see that.<sup>132</sup>

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<sup>129</sup> WERTZ ET AL., *supra* note 9, at 7.

<sup>130</sup> Lisa M. Anllo, *Sexual Life After Breast Cancer*, 26 J. SEX & MARITAL THERAPY 241, 246 (2000).

<sup>131</sup> Michel Dorval, Elizabeth Mannsell, Jill Taylor-Brown, & Marilyn Kilpatrick, *Marital Stability After Breast Cancer*, 91 J. NAT’L CANCER INST. 54, 56–58 (1999).

<sup>132</sup> *Larry King Live: How to Cope with Breast Cancer* (CNN television broadcast, Sept. 15, 2000), available at <http://www.cnn.com/TRANSCRIPTS/0009/15/lkl.00html> (transcript) (last visited Sept. 26, 2000).

Likewise, there is some evidence that men tend to leave women suffering from HIV and from substance abuse problems. In one study of HIV positive women, fear of abandonment was common. In one woman's case, she described her fear by saying, "Well, at first he was like [sic] mad, like I was. And he said we're going to get through this together. And like I told you, two weeks later he left and I never seen [sic] him again."<sup>133</sup>

Finally, even assuming that the family remains intact, women may fear that the "working conditions" of marriage may change. Husbands and family members may not abandon the woman, they may simply treat her differently. One commentator states:

[P]eople frequently are treated differently once their friends and acquaintances discover that they have an illness. In many cases, the discovery leads to a welcomed response of sympathy and comfort, but it often leads to unwelcomed responses of avoidance or excessive solicitousness. In any case, for many people, any change in their relationships will be unwelcome . . . .<sup>134</sup>

Another concurs that "women worry . . . that friends and family members might treat them differently if they knew that they were tainted with a deadly gene."<sup>135</sup> Once individuals know of another's condition, their freedom to carry on a daily life is seriously and irreparably compromised. As one commentator notes:

Informational privacy allows people to pursue their education, careers, friendships, romances, and medical care without the oversight, interference, or unwelcome involvement of others. By controlling personal information, individuals can control the extent to which other people can participate in their lives.

. . . .

Privacy about genetic status is critical to protect couples or women from harassment because they choose to procreate even when they risk having a child with a genetic disease.<sup>136</sup>

Particularly when it comes to reproductive decisions, the consequences of restraining individuals in their conduct fall differently, and more heavily, upon women, whose "bodies and lives are generally more affected than men's."<sup>137</sup>

## V. CONCLUSION

When it comes to privacy of genetic testing results, the concerns of women, including a potential increase in the risk of domestic violence as well as displacement from or alteration of one's life as a spouse or family member, have not been included in the general discourse. Such concerns

<sup>133</sup> Gielen et al., *supra* note 101, at 27.

<sup>134</sup> David Orentlicher, *Genetic Privacy in the Patient-Physician Relationship*, in *GENETIC SECRETS*, *supra* note 7, at 77, 79.

<sup>135</sup> Kolata, *supra* note 128.

<sup>136</sup> Orentlicher, *supra* note 134, at 79, 81.

<sup>137</sup> Mahowald, *supra* note 39, at 81.



need to be addressed, as women are likely to comprise at least half, if not more, of individuals seeking genetic testing. To suggest, as I have in this Article, that one must pay heed to the potential harm to women is to ask how this should be taken into account. That harm to the person seeking genetic testing is a factor worth considering is consistent, to some extent, with the position taken on confidentiality by the ASHG.<sup>138</sup>

As previously stated, in addition to the usual guidelines for when it is appropriate to reveal the results of genetic testing over a patient's objectives—that there is a high probability that harm will occur and that disclosure will avert the harm, that the harm is serious, and that the disclosure is limited to only that information needed to diagnose or treat the disease—the ASHG has added two requirements: 1) the harm to identified relatives must be “highly likely to occur and . . . serious, imminent, and foreseeable,” and the disease must be “preventable, treatable, or medically accepted standards indicate that early monitoring will reduce the genetic risk,” and 2) “the harm from failing to disclose should outweigh the harm from disclosure.”<sup>139</sup>

It is the second of the ASHG's requirements that would demand that an inquiry be made about possible harm from disclosure. Presumably, such a determination would need to be made on a case-by-case basis, especially because not only must the harm, if any, be identified, but it must then be further analyzed by balancing that harm with the harm from failing to disclose—the competing factor. Thus, just as the call has gone out for general practitioners to screen their patients for the existence of domestic violence as part of the general patient history, so too must all health care providers associated with genetic testing make it their business to assess whether their patients are experiencing, or are likely to experience, domestic violence.

It is the other harm, however—a disruption of family relationships—for which, although very real and of utmost importance to a patient, screening may be more difficult. As difficult as domestic violence may be to predict, how is a health care provider to determine what effects the disclosure of genetic information will have on a woman's place and relationship with her family? Can a doctor assess whether the patient's marriage is strong enough to withstand the disclosure, or whether the disclosure will result in an allocation of family resources in ways that will disempower the woman? It would appear difficult if not impossible to make such an assessment with any degree of accuracy.

At this point, one might ask whether the “balancing test,” although seemingly fair on its face, is workable at all. At a minimum, the test can work if the determination of the harm caused by disclosure becomes the sacred province of the woman herself. She must be the one to ascertain, if

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<sup>138</sup> See discussion *supra* notes 6–19 and accompanying text.

<sup>139</sup> MEDICAL ETHICS, *supra* note 14, at 248; Am. Soc'y of Human Genetics Soc Issues Subcomm. on Familial Disclosure, *ASHG Statement: Professional Disclosure of Familial Genetic Information*, 62 AM. J. HUMAN GENETICS 474 (1998).

she can, what the harm of disclosure will be for her in her particular life situation and with her particular family. After all, her failure to voluntarily inform family members is unlikely to be the result of whim or caprice. If she believed that her family would be supportive, and would treat her as she would want to be treated upon disclosure, she likely would not have refused the disclosure in the first place. Her assessment is the most truthful, most nuanced, and most comprehensive available, and therefore, must not only be accorded respect, but rarely, if ever, questioned.

The balancing test, however, is at best a fallback position from one drawn from the absolutist end of the spectrum. The problem with the balancing test is that, even should women acquire some as-yet-unheard-of level of respect that would allow them to name and quantify the potential harm to them, their function would only be to supply one of the factors in the balancing equation. The actual balancing would be done by health care providers. Their job is to identify the other factor—harm from not disclosing. This is a subject of which doctors are likely to have superior knowledge, or knowledge that they will assume to be grounded in “science” rather than “intuition” or “women’s experience.”

The balancing test at first blush appears to provide a place for considering harm to women. On closer examination, however, it is too unpredictable and too risky for women who would prefer to keep their genetic test results to themselves. The history of the place of women patients in the medical profession, the obvious power imbalances between individual women and doctors, and the lack of standards, if any are even possible, in the notion of “balancing” make this a form of resolution that women should reject.

What protects women is the right to disclose what, to whom, when, and where. Women should join the absolutists for all of the reasons that men should: loss of control over information, the possible burden on family members from disclosure, and the simple honoring of a desire for family members not to know. But women have their unique issues to consider as well. The risk of domestic violence and disruption of family relationships are potential harms that fall disproportionately upon women. The formation of law and policy in this area must begin to account for these gender differences.